



**Patient-centered Care Measures
for the National Health Care Quality Report**
(Defining Patient-centered Care)

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Context and Assumptions

This paper outlines a rationale and methods for incorporating measures of patient centered care in the National Health Care Quality Report as a complement to those in other categories of importance – patient safety, effectiveness, promptness and efficiency. To the extent that patient centered care quality measures are stratified for or tailored to specific populations, they are also useful for understanding the equity of health care in America across different ethnic, racial, socioeconomic and demographic groups.

As requested by the Committee, the FACCT Consumer Information Framework (CIF) is used as an organizing structure for identifying measures across consumer relevant quality domains. The CIF includes four components: (1) consumer messages about the quality of health care (2) a multi-dimensional model for identifying and communicating quality information¹ (3) a set of specific measurement topics to consider within each domain, for different population groups and types of health care systems and (4) a set of quantitative and qualitative methods for scoring and communicating quality information to the public. (Bethell 1997, OPM 1999) The model for identifying and communicating quality information sets forth five quality domains:

The Basics

Measures regarding basic aspects of health care quality that are universally relevant such as access to care, communication with providers and customer service.

Staying Healthy

Clinical and patient/caregiver based measures regarding helping people avoid illness and stay healthy through preventive care, reduction of health risks, early detection of illness and education.

Getting Better

Clinical and patient/caregiver based measures regarding helping people recover when they are sick or injured through appropriate and error-free treatment and follow up.

¹ Dimension are (a) measurement domain (e.g. Getting Better); (b) type of measure (e.g. appropriate care, patient experience); (c) lifestage and/or risk group (e.g. elderly minorities); (d) unit of analysis (e.g. health plan, provider group, hospital)

Living with Illness

Clinical and patient/caregiver based measures regarding helping people with ongoing, chronic conditions to take care of themselves, control symptoms, avoid complications and maintain daily activities through appropriate, error-free treatment and effective education and self care support.

Changing Needs

Clinical and patient/caregiver based measures regarding caring for people and their families when needs change dramatically because of disability or terminal illness—with comprehensive and compassionate services, caregiver support, hospice care.

Criteria used for the identification of potential patient centered care quality measures and methods include (1) relevance to consumers, providers, purchasers and policymakers (2) empirical evidence linking the measurement topic to valued outcomes (3) psychometrically valid and reliable measurement methods (4) improvement models or strategies available (5) feasible data collection and reporting strategies available and (6) parsimony with respect to the full set of quality measures to be included in the National Health Care Quality Report.

While measures appropriate for both health care provider, hospital and health plan assessment are included, (1) a detailed plan for sampling and data collection for these and other units of analysis (e.g. home health, long term care, different types of health plans), (2) a detailed conceptual or technical work-up of proposed measures, (3) final recommendations for sampling and (4) which of the specific patient survey items and scales presented should be used to capture information pertinent to the patient centered care quality measures outlined are not within the scope of this paper.

Definition of Patient Centered Care

The preliminary definition of patient centered care set forth by the Institute of Medicine Committee on the National Health Care Quality Report is:

Health care that respects and honors patients' individual wants, needs, and preferences, and that assures that individual patients' values guide all decisions.

This definition requires the systematic inquiry about and responsiveness to patients' needs, wants and preferences at both the clinical and system level. However, it does not fully recognize the importance of the partnership-based style of health care that is the true hallmark of patient centered care. As such, an expanded definition is offered as the basis for the identification of candidate patient centered care quality measures for the National Quality Report on Health Care:

Health care that establishes a working partnership with patients and their families to ensure decisions are made that respect and honor patients' wants, needs, and preferences and to ensure that patients have the education and support they need to act as a central resource in their own health and/or the health of their family.

Using this definition, a practice of patient centered care will incorporate into each health care encounter explicit communication strategies to elicit, understand and take as relevant patients' own understanding of their needs, wants, preferences and values, even if, and perhaps especially if, they run counter to the those of their providers. When applied to health care for people with an established chronic condition, who are at risk for disease or who experience an acute event such as infection or injury, this definition of patient centered care will require many health care providers to shift to a collaborative model of care whereby they work in partnership with patients and their families in defining health care needs, making health care treatment decisions, selecting and implementing treatments and managing care over time.

Specifically, patient centered care requires that the patient health education, health behavior change and patient self-care management and support strategies critical to the prevention and management of both acute or chronic illness be characterized by the patient centered communication, education and partnership demonstrated to be essential to the effectiveness of these strategies (Center for the Advancement of Health 1996, Center for the Advancement of Health 2000).

When applied to individuals from non-dominant ethnic, racial or cultural groups, the definition of patient centered care offered here has important implications for the knowledge, skills, attitudes and policies that both providers and health care organizations need to have in order to ensure culturally competent patient centered care is provided to individuals in these non-dominant groups.

Patient centered care, as defined here, mediates the achievement of other health care system aims such as patient safety, promptness, effectiveness, efficiency and equity. It opens the door for patients to raise issues, questions and concerns that might not otherwise emerge in the more provider-centered model of care—issues, questions and concerns that can dramatically improve provider understanding and the effective treatment of patients. For example, if encouraged by providers, patients may more accurately and thoroughly discuss their medical history and symptoms and share questions and concerns about medical decisions or procedures that may preempt ineffective treatment or errors. They may help ensure medical decisions and care plans are made that take into account their family, workplace and community context and facilitate their ability to follow medical advice. The patients also may make clear behavioral, attitudinal, emotional or cultural factors that can inhibit or facilitate their own ability to stay healthy and/or manage their health condition to achieve good results.

In this context, patient centered care establishes the trust, dialogue and mutual understanding essential for providers and patients alike to become aware of and address the many behavioral, psychological and contextual factors that influence the prevention, management and progression of illness. In this way, patient centered care directly supports a model of care that explicitly incorporates psychological, social and cultural factors along with biomedical factors in the diagnosis, treatment and management of care.

Translated to the level of the care system, a practice of patient centered care requires routine assessment of the health needs, wants, values and preferences of the population served and the design of delivery systems according to what is learned. This practice can impact:

- ◆ what information is made available to consumers to help them understand the health care system and make good health care choices and the language, translation and dissemination of this information
- ◆ what care is made available
- ◆ where and when this care is made available
- ◆ the physical setting for care
- ◆ strategies for educating and supporting providers to practice care in a way that is responsive to the culture, preferences and unique context of their patients

Relevance of Patient Centered Care Quality Measures

Research regarding how consumers, providers, purchasers and policymakers define and value different aspects of health care quality, strongly supports the inclusion of patient centered care quality measures in the National Health Care Quality Report. (Sofaer 2000, Omnibus Study 1999, Hibbard 1996, Bethell 1997, Bethell, 1998, Cleary 1997, AHA/Picker 1996, DiMatteo 1995, Greteis 1993, Adams 1996, Novack 1993) Consumers describe quality topics within the rubric of patient centered care as the most tangible aspect of the health care system:

- ◆ the communication, respect, trust and caring they experience with providers
- ◆ having their unique circumstances and values considered in the diagnosis and treatment of illness
- ◆ understanding options and being involved in making medical decisions
- ◆ their ability to get the information, education and support they need to care for themselves and prevent and manage their own health
- ◆ getting support and follow-up when they are sick or need to manage a complex health condition.

Consumers often describe these features of health care quality as what makes up a good, patient centered health care system. More than a nicety, many consumers make explicit that they view these aspects of quality as precursors to getting the right diagnosis and treatment for themselves, their child or their family member and to understanding and adhering to medical recommendations and achieving good outcomes. When describing what makes up poor quality primary care, preventive care, specialty care, hospital care, home, long term or end of life care, consumers often refer to failures in patient centered care. In the absence of patient centered care, as defined here, patients report experiencing:

- ◆ Hurried and unavailable providers
- ◆ Use of terms and language that creates a basic and unacknowledged barrier to communication
- ◆ Being discouraged from sharing information they view as important to good diagnosis and treatment decisions and adherence to medical advice
- ◆ Not understanding their condition, goals for treatment, why medical recommendations were made or how to follow these recommendations
- ◆ Not having options presented or discussed
- ◆ Not discussing alternative options that they are considering (e.g. natural therapies) or not having these options taken seriously
- ◆ Having little or no dialogue before decisions are made
- ◆ Not having medical decisions explained and being discouraged from challenging those decisions even if they suspect a medical error or misapplication of treatment
- ◆ The artificial segregation of the emotional and intellectual decisions involved in making health care choices
- ◆ Little consideration of their day to day or cultural context and how that affects their ability to stay healthy and follow medical advice
- ◆ Hard, but important, issues avoided – especially if they are personal, emotional, or spiritual
- ◆ Insensitivity to physical pain, emotional distress and confusion about what is happening
- ◆ Unnecessarily uncomfortable, cold or disrespectful physical environment in the carrying out of medical inquiries or procedures

Consumers often suggest that patient centered care requires a philosophy of care that views the patient as an equal partner rather than a passive recipient of care and that takes as relevant the

psychological, emotional and social factors they clearly understand to impact their health and results of care. Frequently, consumers report that, in their experience, this philosophy is not what shapes the current health care system in spite of what they hear as consistent claims by health care providers and systems for such a model of care. Consumers acknowledge that patient centered care may take more time during certain health care encounters and that it is more difficult to practice patient centered care under certain conditions, such as when health care decisions are urgent or patients and providers speak different languages. However, they frequently share their own anecdotal examples of how patient centered care can prevent negative health events and save time and need for services overall.

Patient centered care is critical to the success of patient education, behavior change and self-care management and support strategies aimed at:

- ◆ changing health behaviors such as smoking, alcohol misuse, unhealthy diet, sedentary lifestyle and the unhealthy reactions to emotions, such as violence
- ◆ the adherence to medical treatment recommendations
- ◆ the successful emotional and practical adaptation to an ongoing illness to maximize quality of life and functioning

An estimated 50% of the health status of the population and the majority of health care costs in America are accounted for by the presence and level of management of chronic illness and the lifestyle behaviors such as smoking, alcohol use and unhealthy diet that often contribute to these chronic conditions. (IFF 2000, Fishman 1997) Studies show that up to one half of all recommended treatments are not followed by patients (Dimatteo 1994) and that the greatest weaknesses of existing disease management programs for people with chronic conditions are that

they do not use modern, patient centered self management and support strategies. (Wagner 1999, Center for the Advancement of Health 2000, Goodall 1992, Sobel 1995) Instead these programs often focus only on providing information and do not address patient understanding and use of this information or the psychosocial and contextual factors in their motivation and ability to do so.

In addition, ineffective communication and partnership between patients and providers is likely to contribute to the often high proportion of missed diagnoses for conditions such as depression and diabetes. Even if patient centered care practices had a relatively small impact on the prevention, early detection and effective management of chronic conditions, changing unhealthy lifestyle behaviors and improving patient self care and adherence, their systematic use could still lead to significant advances in health and reductions in health care expenditures.

In addition to direct assessments of the degree to which health care encounters are patient centered care, there are several policy and system level variables that also are relevant. For example, results of National and State surveys of consumers as well as of at least 150 focus groups asking consumers about quality performance report cards and consumer empowerment confirm that the provision of performance information itself and efforts to empower consumers are relevant to the public in evaluating the degree to which the health care system understands and is responsive to consumer and patient needs and preferences. (CHCF 2000, KFF/AHCPR 1996, Hibbard 1996, Bethell 1997, Bethell 1998)

Analogous to the principles of shared decision making and self care management in the context of clinical care, disclosing information about performance to the public and facilitating consumer empowerment allow consumers to assess and advocate for quality care, make better health care

decisions and become educated about their role in shaping the health care system to meet their needs and the needs of the public at large. While significant improvements in the content included in and communication strategies used to share performance reports with consumers are needed, early results suggest that disclosure of performance information is valued by consumers, is inherently relevant from a public policy point of view and can stimulate quality improvement within health care plans and systems. (National Committee for Quality Assurance 1999, Epstein 2000)

Finally, policymakers, providers and purchasers in particular emphasize the importance of organizing and managing health systems to ensure and enhance patient centered care. Systems for accrediting health care organizations often evaluate whether health systems seek to assess the needs of their population, design services to meet these needs, establish programs to ensure the convenience and accessibility of health care services and engage in quality improvement efforts (NCQA 1999, JCAHO). Both public and private sector purchasers often use accreditation results to make contracting decisions with health plans and health systems.

Patient Centered Care Quality Measures

Taking into account (1) consumer input, (2) expert definitions of patient centered care, (3) the demonstrated role of patient centered care in the appropriate and effective prevention, and (4) treatment and management of illness, the following categories and specific measurement concepts for patient centered care quality measures may be considered for the National Health Care Quality Report.

Measure Category #1: Patient Centered Communication and Caring

Specific Measurement Concepts:

- 1A. Communication with Health Care Providers
- 1B. Helpful and Respectful Support Staff

Measure Category #2: Patient Centered Education and Teamwork

Specific Measurement Concepts:

- 2A. Shared Decision Making
- 2B. Getting Needed Information
- 2C. Self Care Management and Support
- 2D. Self Care Efficacy

Measure Category #3: Consumer Empowerment

Specific Measurement Concepts:

- 3A. Consumer Activation
- 3B. Public Disclosure of Performance Information

Measure Category #4: Patient Centered Systems of Care

Specific Measurement Concepts

- 4A. Understanding Population Needs and Preferences
- 4B. Patient Centered Customer Service, Convenience and Comfort
- 4C. Managing for Patient Centered Care

When data is collected in a way that allows these proposed measures to be calculated and reported separately for different ethnic, racial, cultural, socioeconomic or demographic groups, these measures can be used to examine equity of health care quality and, to a large degree, cultural competency of health care providers and systems.²

Not all of the measurement concepts proposed here are mutually exclusive. However, each represents a distinct aspect of care for which unique measurement tools are required. Furthermore, as outlined in Table 1, while many of the specific measurement concepts are relevant for each of the five FACCT Consumer Information Framework quality domains, measure category #2 is most relevant for individuals who are more frequent users of the system, such as those who are at risk for or have a chronic condition or who experience acute infections or injuries requiring urgent treatment and/or hospitalization (Getting Better, Living with Illness).

It should be noted that even though measure categories #1 and #2 both relate to the creation of a partnership-based model of care, “patient education and teamwork” represents a much more specific and expanded notion of partnership and is therefore separated out from “communication

² It is important to note that while the goals for cultural competency in health care are largely represented by the measures listed here, stratified sampling by cultural groups and some tailoring of specific measurement tools is required.

and caring”, which is a core aspect of all care that does not specifically represent the notion of partnership.

Eight of the eleven measurement concepts listed above rely on patient reported information, two are structural measures that rely on information obtained from or about health care providers, health plans or the health care systems as a whole (4A, 4C) and one could be measured using consumer based or system based data (3B). None of the measurement concepts suggests measuring patient satisfaction, per se. Rather they measure patient reported experience of care, patient reported processes of care and patient reported intermediate outcomes of care.

Tested patient based survey tools were found for each of the eight patient based measures. These tools can be used with sampling and scoring strategies to generate the same quality measure for each domain, for specific subsets of the population within domains and for alternative units of analysis, such as providers, health plans, hospitals, home or long term care.

Table 1: Patient Centered Quality Measures Across Consumer Relevant Quality Domains

	The Basics	Staying Healthy	Getting Better	Living with Illness	Changing Needs
Measure Category #1: Patient Centered Communication and Caring					
<i>1A. Communication with Health Care Providers</i> (know patient, listen, explain clearly and in language patient understands, respect, enough time, interested and caring, answer questions, maintain confidentiality/privacy)	✓	✓	✓	✓	✓
<i>1B. Helpful and Respectful Support Staff</i> (helpful, courteous, respectful, friendly)	✓		✓	✓	
Measure Category #2: Patient Centered Education and Teamwork					
<i>2A. Shared Decision Making</i> (describe options, risks and benefits, elicit and consider preferences before deciding, respond to questions, consider context and psychosocial factors, ensure understanding, make reasons for recommendations transparent)	✓		✓	✓	✓
<i>2B. Getting Needed Information</i> (information not kept from patient, told about test results when promised, explain test results and side effects of treatments, told what to expect)	✓		✓	✓	
<i>2C. Self Care Management and Support</i> (collaborative definition of problems, goal setting and care planning, consider contextual factors and readiness of patients to adhere, follow-up, build patient/caregiver knowledge, capacity and confidence to observe own health, take actions to address problems early, change behaviors and seek support, support services available)		✓	✓	✓	✓
<i>2D. Self Care Efficacy</i> (patient confidence to take care of their health, adhere to medical advice, conduct and adjust tasks and activities to manage illness and attenuate its negative impact on life)		✓	✓	✓	

Table 1 (continued):
Patient Centered Quality Measures Across Consumer Relevant Quality Domains

	The Basics	Staying Healthy	Getting Better	Living with Illness	Changing Needs
Measure Category #3: Consumer Empowerment					
<i>3A. Consumer Activation</i> (consumers seek information, ask questions, learn about quality, learn about their health on their own/read books about health)	✓		✓	✓	
<i>3B. Public Disclosure of Performance Information</i> (Critical mass of consumers have timely access to relevant and understandable information about health care performance across relevant domains of quality)	✓	✓	✓	✓	✓
Measure Category #4: Patient Centered Systems of Care					
<i>4A. Understanding Population Needs and Preferences</i> (Routine assessment of the full range of health needs, preferences, attitudes and beliefs that impact health through population surveys, qualitative inquiry and use of public health information; use of information to design systems and strategies)	✓	✓	✓	✓	✓
<i>4B. Patient Centered Customer Service Convenience and Comfort</i> (Helpful service in navigating the system, getting information and getting bills paid. Convenient location and hours of operation that considers culture and work and family demands of the population, comfortable and calming physical setting for primary care, hospital care, conducting procedures, home and long term care).	✓	✓	✓	✓	✓
<i>4B. Managing for Patient Centered Care</i> (System self-assessment regarding ability to provide state of the art patient education, self care management and support; incentives built in to management to ensure patient centered care)	✓	✓	✓	✓	✓

Empirical Support for Patient Centered Care Quality Measures

Each of the eleven measurement concepts outlined has face validity. However, the empirical support linking these measurement concepts to improved outcomes is strongest for four of the eleven:

Measure 1A: communication with health care providers

Measure 2A: shared decision making

Measure 2C: self care management and support

Measure 2D: self care efficacy.

A patient centered model of care characterized by good communication, provision of needed information, shared decision making and self-care management and support has been linked to improvements in outcomes. Research suggests that the patient-provider relationships and trust established, the information exchanged and the problem solving that occurs in the context of a patient centered model of care are the chief mechanisms that link patient centered care to improved outcomes for patients. (DiMatteo 1994, Von Korff 1997, Prochaska 1994, Seeman 1983, Brody 1980) With patient centered care strategies, patient learning and confidence are enhanced, willingness to disclose and discuss complicated symptoms or problems with treatment is stronger and personalized and creative solutions to ensure patient compliance and effectiveness of treatments are more likely.

Research linking patient centered care to outcomes most often measure eight types of outcomes:

(1) adherence to medical regimens

- (2) changing unhealthy behaviors/adopting healthier lifestyle
- (3) satisfaction with care
- (4) psychosocial/emotional health distress
- (5) self-reported health status (e.g. pain, energy level, ability to do things)
- (6) clinical indicators (e.g. cholesterol, blood pressure, blood sugar levels)
- (7) acceptance of recommended procedures (e.g. mammography)
- (8) utilization of acute care services (e.g. hospitalization and the emergency room)
- (9) costs and efficiency of care.

In the context of primary care, a recent study found that adherence to medical advice was three times greater for patients who report that communication with their primary doctor was such that they believe that their doctor has “whole person knowledge” of them and that they trust their doctor (Safran 1998). Other outcomes directly explained by the nature and quality of communication with providers were (1) improved satisfaction and (2) improved self reported health status.

In addition, numerous studies demonstrate that patient education and counseling to prevent or reduce risky behaviors such as smoking, alcohol misuse or unsafe sex are more successful when they are characterized by good communication (listening, inquiring about concerns and preferences, encouraging and answering questions) and self care management and support (collaborative planning for behavior change, routine follow up and support). When conducted in a patient centered manner, preventive education and counseling result in a greater likelihood of changing unhealthy behaviors, adopting good health habits and seeking preventive screening services. (Center for the Advancement of Health 2000, Mullen 1997, Delbanco 1996, Kamb 1998, Prochaska 1996, Curry 1994, Gritz 1992, Anonymous 1996, Fleming 1997, Meenan 1998, Fox 1991)

Communication that leads to “whole person knowledge” and trust is a defining characteristic of state of the art shared decision making, behavior change and self care management and support models of care. (Wagner 2000, Lorig 1999, Von Korff 1997, Braddock 1997, Sobel 1995, Prochaska 1994, Brody 1989, Tobin 1986, Haynes 1976) Specifically, numerous studies have linked improved adherence and self-care practices, reduced health distress, improved satisfaction and/or clinical and self-reported health outcomes to communication whereby patients experience that (1) their perceived needs, wants and preferences are valued and respected, (2) they can ask questions, get the information that they need and negotiate solutions to problems and (3) the psychosocial and contextual aspects of their lives are fully regarded and incorporated into their health care. (CFAH 2000)

Lorig, et al (1999) recently demonstrated that compared to a randomly assigned control group, patients with an array of chronic conditions who were enrolled in a comprehensive patient centered self-care management program experienced significant improvements in adherence to medical regimens (e.g. medications), health behavior change recommendations (e.g. exercise), psychosocial and emotional distress due to illness, self reported health status, reduced occurrence of hospitalization and reduced costs of care. (Lorig 1999)

In studies examining the effectiveness of patient centered self-care management and support programs, similar results have been found for people with either common or rare health conditions. While there are multiple and varying components to the interventions evaluated, the interventions studied in the literature cited below have in common the incorporation of patient centered communication and specific strategies for shared decision making and/or self-care management and

support. Outcomes for people with the following conditions have been shown to improve when patient centered approaches are explicitly incorporated into their care:

1. children and adults with **diabetes** (Aubert 1998, Kinmonth 1998, Rubin 1998, Greenfield and Kaplan, 1988, Greenfield and Kaplan 1985, Kaplan, 1989, Day 1996, Diabetes Care 1996, Weinberger 1995, Goodall 1991)
2. adults with **arthritis** (Hirono 1994, Lorig 1998, Lorig 1993)
3. **preterm infants** (Buehler 1995)
4. women with **breast cancer** (Fallowfield 1992, Spiegel 1989)
5. adults and children with **asthma** (Clark 2000, Greineder 1999, Turner 1998, Dickinson 1997, Lahdensuo 1996, Liptak 1996, Bolton 1991, Rubin 1986)
6. adults with **depression** (Simon 2000, Von Korff 1998, Katon 1995)
7. adults with **hypertension** (Zernike 1998, Bogden 198?)
8. adults with **cancer** (Fawzy 1995)
9. people with **HIV** (Kelly 1993)
10. adults and children with **coronary heart disease** (DeBusk 1994, Becker 1998, Oldridge 1993)
11. adults with **congestive heart failure** (Rich 1995, Dracup 1994, Vinson 1990)
12. caregivers of people at the **end of life** (Emmanuel 2000)
13. adults with **Parkinson's** disease (Montgomery 1994)
14. elderly people who are **frail** (Leveille 98, Naylor 94, Pathy 1992)
15. people requiring **anticoagulation** therapy (Sawicki 1999, Ansell 1999)

We know that not all patients prefer shared decision making or require that patient centered self care management and support strategies be used in order to experience good outcomes. However, since

providers are not good at predicting which patients do and do not value shared decision making or will benefit from state of the art self care management and support strategies (Liptak 1996, Strull, Lo and Charles, 1984), the best practice models of care recommend that patient centered care communication, decision making and self care management and support be incorporated into care and/or offered to all patients. It is important to note that the patient reported “shared decision making” and “self care management and support” measures ask whether providers offer options and ask about patient preferences and the sufficiency of self care information and support. As such, these measures accommodate variations in patient preferences and needs for shared decision making and self care management and support.

In addition to the communication with providers, shared decision making and self care management and support measures (Measures 1A, 2A and 2B), self-care efficacy is an intermediate outcome measure for which reasonable empirical support exists (Measure 2C). Self care efficacy occurs when patients report confidence in their knowledge and ability to perform self-care management tasks. Several researchers have demonstrated the relationship between self reported self care efficacy and health outcomes. (Madden 1992, Grembowski 1993, Seeman 1983, O’Leary 1995, Day 1995)

Regarding the measurement concepts related to Consumer Empowerment and Patient Centered Systems of Care, little empirical evidence exists linking these features of the health care system to improved patient outcomes such as health status, improved adherence, enhanced satisfaction, improved cultural competency, reduced psychosocial distress or improved efficiency of health care. However, extensive literature does exist to describe the theoretical and practical importance of performance reporting, consumer empowerment and strategies to ensure the design of patient centered systems of care. (Epstein 2000, Hibbard 1997, Durch 1996, Wagner 1998, Wagner 1999,

Brach, 2000, Tirado, 1998, Mason, 1995, Andrulis, 1999) Inclusion of such measures in the National Health Care Quality Report would have to be based primarily on the face validity and policy importance of these measurement concepts.

Summary of Criteria Review

To assist the Committee in selecting patient centered care quality measures, each candidate measurement concept outlined here is rated on a scale of one to five, with five being the highest rating.

Table 2 provides an overall rating of each of the eleven measurement concepts in terms of:

- (1) the perceived **relevance** of the measurement concept as an indicator of health care quality
- (2) the level of **empirical evidence** linking the measure to valued outcomes
- (3) the psychometric **validity and reliability** of available survey tools for the eight patient based measurement concepts
- (4) whether **improvement** models and/or strategies are available
- (5) the **feasibility** of collecting required data.

This rating is based on the review of the literature and available measurement tools conducted for this paper. Reports from at least twenty consumer based focus groups and/or surveys generally representative of the US population in terms of age, ethnicity and socioeconomic status were required to rate relevance as 3 or higher. At least two large cross-sectional and/or randomized controlled studies were required to rate “empirical evidence” as being a level three or higher. Published literature demonstrating the psychometric validity and reliability of survey tools was required to rate validity and reliability of tools as 3 or higher. Large scale and multiple fieldings of measurement tools were required to rate feasibility as 3 or higher.

Table 2: Rating of Patient Centered Care Quality Measures on Key Criteria

	Perceived Relevance	Empirical Evidence	Psychometrically valid and reliable measurement tools	Demonstrated strategies for improvement	Feasible data collection strategy
Measure Category #1: Patient Centered Communication and Caring					
<i>1A. Communication with Health Care Providers</i>	5	4	4	3	5
<i>1B. Helpful and Respectful Support Staff</i>	2	2	3	3	5
Measure Category #2: Patient Centered Education and Teamwork					
<i>2A. Shared Decision Making</i>	4	4	4	4	4
<i>2B. Getting Needed Information</i>	5	3	3	3	4
<i>2C. Self Care Management and Support</i>	5	4	3	4	4
<i>2D. Self Care Efficacy</i>	4	4	4	3	4
Measure Category #3: Consumer Empowerment					
<i>3A. Consumer Activation</i>	3	2	3	3	5
<i>3B. Public Disclosure of Performance Information</i>	3	2	2	2	4
Measure Category #4: Patient Centered Systems of Care					
<i>4A. Responding to Population Needs and Preferences</i>	3	2	4	4	2
<i>4B. Patient Centered Customer Service, Convenience and Comfort</i>	4	2	2	3	4
<i>4C. Managing for Patient Centered Care</i>	3	1	4	3	2

As noted earlier, while each of the eleven measurement concepts outlined has face validity, the empirical support linking these measurement concepts to improved outcomes is strongest for four of the eleven:

Measure 1A: communication with health care providers

Measure 2A: shared decision making

Measure 2C: self care management and support

Measure 2D: self care efficacy.

As noted in Table 2, these four measures also meet criteria for relevance, feasibility and psychometric validity and reliability. While strategies for improving performance are assumed to exist based on the many studies conducted that employed strategies to ensure high performance in each of these four areas, studies demonstrating proven quality improvement methods are rare. Finally, existing measurement tools for “self care management and support” do meet criteria. However, additional work is recommended to ensure the content validity of available tools for measuring quality in this important area.

The final criteria for considering patient centered care measures is parsimony within the metaset of quality measures selected by the Committee. A review of parsimony is only possible when the Committee makes the full range of candidate measures available.

Measurement Tools and Data Collection Strategies

To translate the patient centered care measurement concepts outlined here into carefully specified quality measures, specific measurement tools and data collection strategies must be identified. As noted earlier, tested patient/consumer survey tools for each of the patient based measures were found. Tools for Consumer Empowerment and Patient Centered Systems of Care are less well developed and tested. However, several candidate tools were found are referenced in Appendix A.

Measurement Tools

Examples of survey items for proposed measures and the populations for which these measures may be most appropriate (sampling frame) are outlined in Table 3. For all patient survey based measures, several items within a survey are scored together to create a scale representing the measurement concepts (e.g. communication with providers, shared decision making). A more extensive review of examples of patient based survey items as well as tools for system level measures is included in Attachment A. Specific results regarding the psychometric validity and reliability of candidate surveys, detailed ideas for sampling, scoring and presenting patient centered care quality measures and estimated costs of survey administration are available upon request.

Sampling Frame

While it is not the goal of this paper to provide a specific sampling plan, it is important to clarify the central concept for sampling suggested in Table 3. Specifically, while many of the measures for the Getting Better and Changing Needs domains are likely to require separate sampling and data collection efforts, most of the measures for The Basics, Staying Healthy and Living With Illness domains can be obtained through a single population based survey strategy. In this context,

screening items are available that can be included in a population based survey such as the National Health Interview Survey (NHIS), the Medical Expenditures Panel Survey (MEPS), Behavioral Risk Factor Surveillance Survey (BRFSS) or the Consumer Assessment of Health Plans Survey (CAHPS). Doing this will allow for the identification of people with chronic conditions (Living With Illness) and/or people for whom risk reduction strategies are recommended (Staying Healthy). In this way, specific survey items can be asked and/or scored separately for (or only for) these subgroups. An example of a five item screening tool that is being used in the upcoming fielding of the MEPS to identify children with chronic conditions is included in Attachment A. A similar tool is currently being tested for adults.

As noted earlier, to facilitate the examination of the equity of the health system, quality measures can be created for different demographic groups by further including survey items about age, gender, ethnicity, race and insurance status.

Finally, if it does not violate the confidentiality of survey respondents and it is methodologically possible to collect clinical and/or administrative data for the same individuals who complete surveys (as it may be for MEPS, for example), a particularly powerful picture of performance can be generated by matching clinical data with survey data. For example, we can learn about both the self reported quality of care for people with chronic conditions and also whether these same people received appropriate care (e.g. screening tested, required medications, patient education and counseling).

More complicated measurement and sampling strategies (e.g. disease by disease assessments of patient centered care) are not recommended due to the difficulty of and high cost associated with

such an approach. However, if there is interest in conducting disease specific assessment (e.g. for women with breast cancer, people with major depressive disorder, people with asthma, diabetes, heart disease or cancer), patient centered care measurement tools are available and can be provided upon request.

Table 3: Sampling Frame and Example Survey Items for Selected Patient Centered Care Measures

Measurement Concept	Applicable Quality Domains	Sampling Frame	Example Survey Items
1A. Communication with Health Care Providers	The Basics Staying Healthy Getting Better Living with Illness Changing Needs For parsimony, cycle data collection for adult and child population for The Basics year to year.	-All adults (TB) -Adults with chronic conditions (LWI) (non-categorically defined) -Adults who have been hospitalized (GB) -Parents of children age 0-13 (TB) -Parents of children with chronic conditions (non-categorically defined) -Teens age 14-18 -Caregivers of people who have died (CN)	<u>CAHPS Items (also in BREFS) NCQA, 2000:</u> In the last 12 months, how often did doctors or other health providers: <ul style="list-style-type: none"> ◆ <u>explain things</u> in a way you could understand? ◆ <u>listen carefully to you?</u> ◆ show <u>respect for what you had to say?</u> (Response options: never, rarely, sometimes, usually, always) <u>PCAS/FACCT 15 Items (Safran and Rogers, 2000)</u> Thinking about how well your doctor knows you , how would you rate the following? <ul style="list-style-type: none"> ◆ Doctor's knowledge of what worries you most about your health ◆ Doctor's knowledge of you as a person (your values and beliefs) (Response Options: Very poor, poor, fair, good , very good, excellent) Thinking about the personal aspects of the care you receive from your regular doctor, how would you rate your doctor's caring and concern for you? (Response options: Very poor, poor, fair, good , very good, excellent)
1B. Helpful and Respectful Support Staff	The Basics Getting Better Living with Illness	-All adults -Adults who have been hospitalized -Adults with chronic conditions -Parents of children who have a chronic condition	<u>CAHPS Items NCQA, 2000:</u> <u>In the last 12 months</u> , how often <ul style="list-style-type: none"> ◆ were office staff at a doctor's office or clinic as <u>helpful</u> as you thought they should be? ◆ did office staff at a doctor's office or clinic treat you with <u>courtesy and respect?</u> (Response options: never, rarely, sometimes, usually, always)
2A. Shared Decision Making	Getting Better Living with Illness Changing Needs	-All adults who have been hospitalized Adults who have a chronic condition -Parents of children 0-13 whose child has a chronic condition -Caregivers of people who have died	<u>Diabetes Quality Improvement Project (DQIP) Survey Items, NCQA, 2000</u> How often do your doctors or other health care professionals <ul style="list-style-type: none"> ◆ offer you choices in your medical care? ◆ discuss the pros and cons of each choice with you? ◆ get you to state which choice or option you would prefer? ◆ take your preferences into account when making treatment decisions? (Response options: all, most, some, a little or none of the time)
2B. Getting Needed Information	The Basics Getting Better Living with Illness	-All adults -Adults who have been hospitalized -Adults who have a chronic condition -Parents of children with a chronic condition	<u>DQIP Survey Items, NCQA, 2000</u> How are your doctors or other health care professionals at <ul style="list-style-type: none"> ◆ telling you everything: not keeping things from that you should know? ◆ letting you know test results when promised? ◆ explaining side effects of medications? ◆ telling you what to expect from your disease or treatment? (Response options: poor, fair, good, very good, excellent)

Table 3 (continued): Sampling Frame and Example Survey Items for Selected Patient Centered Care Measures

Measurement Concept	Applicable Quality Domains	Sampling Frame	Example Survey Items
2C. Self Care Management and Support	Staying Healthy Getting Better Living with Illness	-All adults with one or more risky behaviors -Adults who have been hospitalized -Adults with a chronic condition -Parents of children who have a chronic conditions	<u>FACCT ONE Survey. (FACCT, 1999)</u> Overall, how helpful has the care you have received from your current doctors or health providers been to you in the following areas: <ul style="list-style-type: none"> ◆ Making clear the specific goals for (treating your condition/changing health behavior) ◆ Helping you understand what you need to do (for your condition/to improve health behaviors) ◆ Helping you understand how to care for yourself ◆ Keeping you motivated to do the things you need to do (for your condition/to stay healthy) (Response options: very helpful, helpful, neutral, not too helpful, not helpful at all) <u>Picker Institute Adult Ambulatory Care Survey</u> <ul style="list-style-type: none"> ◆ Did the provider explain what to expect with your health or illness in the future? ◆ Did the provider explain what to do if problems or symptoms continued, got worse or came back? (yes/no/not applicable)
2D. Self Care Efficacy	Staying Healthy Living with Illness	-All adults -Adults with a chronic condition -Parents of children with a chronic condition	<u>Examples from Outcomes Measures for Health Education (Lorig, Stewart, Ritter, et. al. 1996)</u> We would like to know how confident you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time. Having an illness often means doing different tasks and activities to manage your condition. How confident are you that you can <ul style="list-style-type: none"> ◆ do all the things necessary to manage your condition on a regular basis? ◆ can judge when the changes in your illness mean you should visit a doctor? ◆ do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor? ◆ reduce the emotional distress caused by your health condition so that it does not affect your everyday life? ◆ do things other than just taking medication to reduce how much your illness affects your everyday life? (Response options: Not at all confident 1, 2, 3, 4, 5, 6, 7, 8, 9, 10 Totally confident) <u>RWJ/FACCT/Harris National Survey (May, 2000)</u> Thinking about your overall ability to take care of your general health – eating right, getting check-ups, taking medicine, deciding when to see the doctor – how confident are you that you know what do to? (Response options: very confident, somewhat confident, not very confident, not at all confident)
3A. Consumer Activation	The Basics Living with Illness	-All Adults -Adults with chronic conditions -Parents of children with chronic conditions	<u>RWJ/FACCT/Harris National Survey (May, 2000)</u> Thinking about experiences you have had with health care professionals, such as doctors, how likely or unlikely you are to do the following: <ol style="list-style-type: none"> a. Get a second opinion on a serious diagnosis b. Look up information about a new prescription such as side effects and precautions c. Ask questions about medical equipment used for your medical treatment d. Get information on your health care professional's background before seeing them e. Try to learn about the quality of care provided before picking a doctor or health plan (Response options: very likely, somewhat likely, not very likely, not at all likely)

Existing Data and Data Collection Mechanisms

For several of the patient centered care quality measures outlined in this paper, existing sources of data do exist. In addition, required survey items could be included in one or more of the several national and/or statewide surveys that are conducted on a routine or periodic basis. Finally, models for new data collection are available should new data collection mechanisms be required. Table 4 provides a summary of existing data sources, national and/or state surveys to “piggyback” onto and ideas for new data collection.

It should be noted that some surveys that are known to exist and might be useful for the Committee to consider are not listed as they are in the preliminary stages of development and not enough is known to accurately portray them here (e.g. CAHPS Behavioral Health Survey, CAHPS Medical Group Practice Survey, CAHPS items regarding cultural competency, FACCT/CAHPS items for children with special health care needs).

It is assumed that the most relevant sources of data are those that are nationally representative and that can be specified for specific units of analysis such as providers, health plans and hospitals. The measurement tools and data collection strategies summarized here allow for patient centered quality measures to be developed for nationally representative samples of people and for health care providers, health plan or systems, hospitals and facilities caring for people at the end of life.

Table 4: Existing and Potential Sources of Data for Patient Centered Care Quality Measures

Quality Domain	Existing Sources of Data	Relevant National Surveys (piggyback)	Ideas for New Data Collection
The Basics	Measures 1A, 1B 1. Behavioral Risk Factor Surveillance Survey (1A) – State specific 2. NCQA/HEDIS CAHPS 2.0H data for some HMOs (1A, 1B) 3. HCFA – CAHPS data for Medicare fee for service providers (1A, 1B) 4. RWJ/FACCT National Survey (1A for adults and teens) 5. National CAHPS data base	Measure 3A and 3B: 1. National Workgroup on Consumer Information Survey (being designed as a follow up to the original AHCPR/KFF Survey on Consumers and Quality Information) Potentially all patient/consumer survey based measures: 2. National Health Interview Survey (NHIS) 3. Medical Expenditures Panel Survey (MEPS)	1. Use an online data collection model such as employed in the recently completed RWJ/FACCT National Survey (telephone survey conducted to create sampling weights). This method is quick and relatively efficient.
Staying Healthy	Measures 1A: 1. SLAITS Survey of Families with Young Children (0-3) Measures 1A, 2A, 2B: 2. RWJ/FACCT National Survey (adults and teens)	1. Behavioral Risk Factor Surveillance Survey (BRFSS) 2. Youth Risk Behavior Survey (YRBS) 3. NHIS 4. National Ambulatory Medical Care Survey (NAMCS)	2. Identify a National panel of consumers. Collect survey, administrative and chart data to allow a full profile of performance across all quality domains (e.g. Staying Healthy, Living with Illness); types of measures (e.g. safety, appropriateness, patient centered care.); lifestyles/risk groups (e.g. elderly, minorities) and units of analysis (e.g. plans, providers).
Getting Better	Measures 1A, 1B, 2A, 2B, 2C: 1. Picker Hospital Survey Data from several states	1. National Survey of Ambulatory Surgery (NSAS) 2. NAMCS Concept: Include survey items to identify people who visited the ER or who had been hospitalized and then administer survey relevance to create measures.	
Living With Illness	Measures 1A, 2A, 2B: 1. SLAITS Survey for Children With Special Health Care Needs (0-17) Measures 1A, 2A, 2B, 2C, 2D, 3A: 2. RWJ/FACCT National Survey (general adults chronic condition population, specific samples/measures for depression, diabetes, pediatric asthma) Measures 1A, 2A, 2B: 3. HCFA Diabetes Quality Improvement Project Survey Data	1. MEPS 2. NHIS 3. NAMCS Concept: Include survey items to screen for chronic conditions for both children and adults. Tools available.)	
Changing Needs	Measure 1A, 2A, 2C: 1. RWJ/FACCT National Survey (end of life)	1. National Nursing Home Survey 2. National Mortality Followback Survey	

Summary and Conclusion

Echoing the known relevance of patient centered care to the public, a 1999 survey of Americans found that second only to family members, relationships with health care providers are the most important relationships people report having. (Omnibus Study 1999) In this same study, 96% of both physicians and patients define a good relationship as one characterized by compassion, understanding and partnership involving two-way communication and decision making. Over 90% of physicians consider the best patients to be informed and educated patients. (Collins 1998)

Including patient centered care quality measures in the National Health Care Quality Report is not only essential to the face validity of any such report, but their inclusion is also needed to legitimize patient centered care as the most permeating aspect of care experienced by patients. Incorporating patient centered care quality measures in the National Health Care Quality Report means embracing a partnership-based model of care that explicitly incorporates psychological, social and cultural factors along with biomedical considerations in the diagnosis, treatment and management of care. Doing so will encourage health care providers and systems to focus on improving quality in this area and on achieving the tangible improvements in health and health care.

The inclusion of patient centered care measures of health care quality in the National Health Care Quality Report is supported by the strong intersection of evidence for components of patient centered care, such as shared decision making and self-care management and support, and consumer provider, purchaser and policymaker interest in this aspect of health care. While work remains to develop a full panel of measurement tools for capturing information about the quality of the health care system in the area of patient centered care, valid and reliable tools and strategies are available to

allow for the immediate use of many of the patient centered care quality measures outlined in this paper.

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ATTACHMENT A
EXAMPLE MEASUREMENT TOOLS FOR CREATING PATIENT CENTERED CARE
QUALITY MEASURES FOR A NATIONAL HEALTH CARE QUALITY REPORT

Measure Category #1: Patient Centered Communication and Caring
Example Survey Items

Specific Measurement Concept: Communication with Health Care Providers

Examples from the Consumer Assessment of Health Plans Survey

FOR PEOPLE WHO HAVE SEEN A HEALTH CARE PROVIDER IN THE LAST 12 MONTHS

[Note: Items 8c, 8d and 8e are also included in the Behavioral Risk Factor Surveillance Survey]

8c. In the last 12 months, how often did doctors or other health providers explain things in a way you could understand? (Response options: never, rarely, sometimes, usually, always)

8d. In the last 12 months, how often did doctors or other health providers listen carefully to you? (Response options: never, rarely, sometimes, usually, always)

8e. In the last 12 months, how often did doctors or other health providers show respect for what you had to say? (Response options: never, rarely, sometimes, usually, always)

8f. In the last 12 months, how often did doctors or other health providers spend enough time with you? (Response options: never, rarely, sometimes, usually, always)

Examples from the Group Health Association of America (GHAA) Survey

FOR PEOPLE WHO HAVE SEEN A HEALTH CARE PROVIDER IN THE LAST 12 MONTHS

24. Thinking about your own health care, how would you rate friendliness and courtesy shown to you by your doctors?

25. Thinking about your own health care, how would you rate personal interest in you and your medical problems?

26. Thinking about your own health care, how would you rate respect shown to you, attention to your privacy?

27. Thinking about your own health care, how would you rate reassurance and support offered to you by your doctors and staff?

29. Thinking about your own health care, how would you rate amount of time you have with doctors and staff during a visit?

(Response options: Poor, fair, good, very good, excellent)

Examples from the Primary Care Assessment Survey-FACCT-15 (Safran and Rogers, 2000)

FOR PEOPLE WHO HAVE SEEN THEIR PRIMARY DOCTOR IN THE LAST 12 MONTHS

7. Thinking about how well your doctor **knows you**, how would you rate the following?

10a. Doctor's knowledge of what **worries** you most about your health

10b. Doctor's knowledge of **you as a person** (your values and beliefs)

(Response options: Very poor, poor, fair, good, very good, excellent)

8. Thinking about the **personal aspects** of the care you receive from your regular doctor, how would you rate your doctor's **caring and concern** for you? (Response options: very poor, poor, fair, good, very good, excellent)

Example items from items by Starfield, Flocke and Stange (recommended to NCQA for primary care assessment).

1. This doctor knows me well as a person
2. This doctor understands what is important to me regarding my health
3. This doctor always takes my beliefs and wishes into account in caring for me
4. This doctor always explains things in a way that meets my needs
5. I feel comfortable telling this doctor about my worries or problems
6. This doctor understands how my family affects my health
7. This doctor would meet with members of my family if I thought it would be helpful
8. This doctor uses her/his knowledge of my community to take care of me

Response Options: Strongly Disagree to Strongly Agree (six point scale)

NOTE: Psychometric validity and reliability data not reviewed/available

Example items from the Diabetes Quality Improvement Project Survey

FOR PEOPLE WHO HAVE SEEN THEIR PRIMARY DOCTOR OR OTHER HEALTH CARE PROVIDER IN THE LAST 12 MONTHS

10a. Thinking about the doctor or health professional who you see most often, would you recommend this doctor or health professional to a friend who wanted someone with an excellent personal manner? (Response options: definitely no, probably no, not sure, probably yes, definitely yes)

Examples from RWJ/FACCT/Harris Teen Survey (RWJ/FACCT, May, 2000)

FOR ADMINISTRATION TO ADOLESCENTS WHO HAVE SEEN A HEALTH CARE PROVIDER IN THE PAST 12 MONTHS

My child's doctor, nurse, or other health care provider:

- a. Makes it easy to be open
- b. Listens carefully to me
- c. Makes sure I understand the health risk of my behaviors
- d. Gives me the chance to talk about everything I want to
- e. Makes me want to see him/her again
- f. Causes worry that he/she might tell my parents or guardian about things I did not want them to know

(Response options: strongly agree, agree somewhat, neither agree nor disagree, disagree somewhat, strongly disagree)

Examples from the Surrogate Hospital Afterdeath Interview (J. Teno)

FOR CAREGIVERS OF PATIENTS WHO HAVE DIED AND EXPERIENCED A HOSPITALIZATION SHORTLY BEFORE THEY DIED

Now I would like to ask you some questions about (patient's) final hospitalization:

85. Did you feel that anyone at (hospital) really understood what you and your family were going through? (yes/no/don't know)
86. Did someone talk with you and/or (patient) about your religious or spiritual beliefs in a sensitive manner? (yes/no/don't know)
88. During the last hospitalization, was there anything the health care team did that made it harder to practice your religious or spiritual beliefs? (yes/no/don't know)
90. Did the hospital setting interfere with (patient) finding peace in (his/her) last days? (yes/no/don't know)
91. Did a doctor really listen to you and (patient) about your hopes, fears, and beliefs as much as you wanted? (yes/no/don't know)
93. Did a member of the health care team talk with you about what would happen at the time of death? (yes/no)
94. Did a member of the health care team talk with you about what it would be like for you after (patient's) death? (yes/no)
1. Did a member of the health care team suggest someone you could turn to for help if you were feeling overwhelmed? (yes/no)
103. Would you have liked the health care team to be more sensitive to your feelings

NOTE: Psychometric validity and reliability data not reviewed/available

Example items from the Client Cultural Competency Inventory (Switzer, Sholle, Johnson, 1998) – Focus on cultural competency and mental health treatment

1. The caregiver uses everyday language that we can understand
2. The caregiver involves other family members in the therapy process whenever possible
3. The caregiver makes negative judgments about us because of the ways that we are different from him/her (such as race, income level, job or religion).

NOTE: Only very limited information on psychometric validity and reliability is available.

Example items from “Monitoring the Managed Care of Culturally and Linguistically Diverse Population” – Focus on cultural competency and managed care (Tirado, 1998)

1. When discussing diagnosis and treatment related to my condition , my doctor asks if I would like to include family members in the discussion
2. I don't have time during my visit with my doctor to ask the questions I would like
3. My doctor asked if I use healing methods traditional to my culture to treat my condition
4. I am clear how to follow my doctor's orders
5. I feel satisfied with the way my doctor treats me as a person
6. My doctor asks about the role of family in my health care

Response Options: Not at all, seldom, usually, often, always

NOTE: Information about the validity and reliability of these is not available

Specific Measurement Concept: Helpful and Respectful Support Staff

Example items from the Consumer Assessment of Health Plans Survey

FOR PEOPLE WHO HAVE SEEN A HEALTH CARE PROVIDER IN THE LAST 12 MONTHS

8a. In the last 12 months, how often were office staff at a doctor's office or clinic as helpful as you thought they should be? (Response options: never, rarely, sometimes, usually, always)

8b. In the last 12 months, how often did office staff at a doctor's office or clinic treat you with courtesy and respect? (Response options: never, rarely, sometimes, usually, always)

Examples from the Group Health Association of America (GHAA) Survey

28. Thinking about your own health care, how would you rate friendliness and courtesy shown to you by staff?

Measure Category #2: Patient Centered Education and Teamwork
Example Survey Items

Specific Measurement Concept: Shared Decision-Making

Example items from the Diabetes Quality Improvement Project Survey (HCFA/NCQA, 2000)

FOR PEOPLE WITH A CHRONIC CONDITIONS AND/OR PEOPLE WHO HAVE SEEN A HEALTH CARE PROVIDER IN THE LAST 12 MONTHS

7c. How are your doctors or other health care professionals at explaining treatment alternatives? (Response options: poor, fair, good, very good, excellent)

7d. How are your doctors or other health care professionals at including you in treatment decisions? (Response options: poor, fair, good, very good, excellent)

6a. How often do your doctors or other health care professionals offer you choices in your medical care? (Response options: all, most, some, a little or none of the time)

6b. How often do your doctors or other health care professionals discuss the pros and cons of each choice with you? (Response options: all, most, some, a little or none of the time)

6c. How often do your doctors or other health care professionals get you to state which choice or option you would prefer? (Response options: all, most, some, a little or none of the time)

6d. How often do your doctors or other health care professionals take your preferences into account when making treatment decisions? (Response options: all, most, some, a little or none of the time)

Example items from the Client Cultural Competence Inventory (Switzer, Scholle, Johnson and Kelleher, 1998) - Focus on cultural competency and mental health treatment

1. The caregiver makes it clear that we as a family, not the professional, are responsible for deciding what is done for our child and family
2. The caregiver encourages us to help evaluate our child's progress
3. The caregiver accepts our family as important members of the team that helps my child
4. The caregiver helps us get services that we need from other agencies or programs
5. The caregiver encourages us to meet with other community professionals (such as ministers or traditional healers).
6. The caregiver involves other family members in the therapy process whenever possible.

NOTE: Only very limited information on psychometric validity and reliability is available.

Examples items from the Surrogate Hospital Afterdeath Interview (J. Teno)

FOR CAREGIVERS OF PATIENTS THAT HAVE DIED

18. Did a doctor talk with you or (patient), in a way that was easily understandable, about the chances that (he/she) would survive the last hospitalization? (yes/no/don't know)
19. During the last hospitalization, did a doctor tell you or (patient) about choices for treatment in a way you could understand? (yes/no/don't know)
24. To what extent were (patients) wishes followed in the medical treatment (he/she) received during the last hospitalization? Were they followed: a great deal, very much, moderately, very little, not at all, don't know.
74. Did a doctor or nurse talk with you or (patient) about how pain would be treated during the last hospitalization? (yes/no)
75. During the last hospitalization did a doctor or nurse tell you or (patient) about the medicine for pain in a way you understood? (yes/no/don't know)
99. Did you or (patient) want to be more involved in making decisions about (patient's) care during the last hospitalization? (yes/no/no decisions made)
100. Do you feel that you or (patient) would have made different decisions about (his/her) care if the health care team had given you more information? (yes/no)
104. Did you feel that the doctors were as helpful as you wanted in explaining (patient's) condition during (his/her) last hospitalization? (yes/no)
- 105.** Do you feel that (patient's) doctor provided you with enough information so that there were no surprises or unplanned medical events in (his/her) last hospitalization?

NOTE: Information about the psychometric validity and reliability was not reviewed/available.

Example items from the Diabetes Quality Improvement Project Survey (NCQA, 2000)

FOR PEOPLE WITH A CHRONIC CONDITIONS AND/OR PEOPLE WHO HAVE SEEN A HEALTH CARE PROVIDER IN THE LAST 12 MONTHS

7a. How are your doctors or other health care professionals at telling you everything; not keeping things from that you should know? (Response options: poor, fair, good, very good, excellent)

7b. How are your doctors or other health care professionals at letting you know test results when promised? (Response options: poor, fair, good, very good, excellent)

7e. How are your doctors or other health care professionals at explaining side effects of medications? (Response options: poor, fair, good, very good, excellent)

7f. How are your doctors or other health care professionals at telling you what to expect from your disease or treatment? (Response options: poor, fair, good, very good, excellent)

Examples from the Picker Institute Adult Ambulatory Care Survey (Sample Questions)

FOR PEOPLE WITH A CHRONIC CONDITIONS AND/OR PEOPLE WHO HAVE SEEN A HEALTH CARE PROVIDER IN THE LAST 12 MONTHS

Tests and Therapy:

- a. Did someone tell you how and when you would find out the results of your tests?
- b. After tests were done, did someone explain the results to you in a way that you could understand? (yes/no/not tests done)

Examples from the Picker Institute Adult Inpatient Survey (Sample Questions)

FOR PEOPLE WHO HAVE BEEN HOSPITALIZED WITHIN THE LAST YEAR

Note: Many of the example items below relate to other measurement concepts within Education and Teamwork.

Respect for Patient's Values, Preferences, and Expressed Needs:

- a. Did you have enough say about your treatment in the hospital?
- b. Did the doctors or nurses ever talk in front of you as if you weren't there?

Information and Education:

- a. When you had important questions to ask a [doctor][nurse], did you always get answers you could understand?
- b. Did a doctor or nurse always explain the results of tests in a way you could understand?
- c. While you were in the emergency room, did you get as much information about your medical condition and treatment as you wanted to get?

Physical Comfort:

- a. When you needed help with things like eating, bathing, or getting to the bathroom, did you usually get it in time?
- b. How many minutes after you used the call button did it usually take, on average, before you got the help you needed?
- c. Did you have enough say about pain control during labor and delivery?

Emotional Support and Alleviation of Fear and Anxiety:

- a. How easy was it for you to find someone on the hospital staff to talk to about your personal concerns?
- b. Did you get as much help as you wanted from someone on the hospital staff in figuring out how to pay your hospital bill?

Continuity and Transition:

- a. Did someone on the hospital staff tell you about important side effects from your medicines to watch for when you went home?
- b. Did someone on the hospital staff tell you what danger signals about your illness (or operation) to watch for after you went home?

Examples from the FACCT Asthma Care Survey (also used in RWJ/FACCT National Survey Project, 2000)

FOR PEOPLE WITH A CHRONIC CONDITION

25. Overall, how helpful has the care you have received from your current doctors or health providers been to you in the following areas:

- a. Making clear the specific goals for treating your (condition)
- c. Helping you understand what you need to do for your (condition)
- d. Helping you understand how to care for yourself and how to do it
- e. Keeping you motivated to do the things you need to do for your (condition)

(Response options: very helpful, helpful, neutral, not too helpful, not helpful at all)

Examples from the Primary Care Assessment Survey/FACCT-15 (Safran and Rogers, 2000)

FOR PEOPLE WITH A CHRONIC CONDITION AND/OR WHO HAVE SEEN A HEALTH CARE PROVIDER IN THE LAST 12 MONTHS

9. Thinking about **talking** with your regular doctor please answer the following:

7a. How would you rate the thoroughness of your doctor's questions about your symptoms and how you are feeling? (Response options: Very poor, poor, fair, good, very good, excellent)

7b. How often do you leave your doctor's office with **unanswered questions**? (Response options: always, almost always, a lot of the time, some of the time, almost never, never)

10. How often does your regular doctor seem **informed and up-to-date** about the care you received from specialists that he/she sent you to (for example: what was done, what was found) (Response options: never, almost never, some of the time, a lot of the time, almost always, always, not applicable no specialists seen)

11. Thinking about the **technical aspects** of your care, how would you rate the thoroughness of the doctor's **physical examination** of you to check a health problem you have? (Response options: very poor, poor, fair, good, very good, excellent)

1. Thinking about the times you have needed to **see or talk to** your doctor, how would you rate your ability to **speak to** your doctor by phone when you have a question or need medical advice? (Response options: Very poor, poor, fair, good, very good, excellent)

Examples from Outcomes Measures for Health Education (Lorig, Stewart, Ritter, et al, 1996)

FOR PEOPLE WHO HAVE A CHRONIC CONDITION

We would like to know **how confident** you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident are you that you can ask your doctor things about your illness that concern you?
2. How confident are you that you can discuss openly with your doctor any personal problems that may be related to your illness?
3. How confident are you that you can work out differences with your doctor when they arise?

(Response options: Not at all confident 1, 2, 3, 4, 5, 6, 7, 8, 9, 10 Totally Confident)

Examples from the Group Health Association of America (GHAA) Survey

FOR PEOPLE WITH A CHRONIC CONDITION OR WHO HAVE SEEN A HEALTH CARE PROVIDER IN THE LAST 12 MONTHS

18. Thinking about your own health care, how would you rate explanations of medical procedures and tests?
19. Thinking about your own health care, how would you rate attention given to what you have to say?
20. Thinking about your own health care, how would you rate advice you get about ways to avoid illness and stay healthy?

(Response options: Poor, fair, good, very good, excellent)

Examples from the Picker Institute Adult Ambulatory Care Survey (Sample Questions)

FOR PEOPLE WHO HAVE SEEN A HEALTH CARE PROVIDER IN THE LAST 12 MONTHS

Information:

- a. Did the provider explain what to expect with your health or illness in the future?
- b. Did the provider explain what to do if problems or symptoms continued, got worse or came back? (yes/no/not applicable)

Emotional Support:

- a. Did you have concerns that you wanted to discuss but did not?

Examples from the Child and Adolescent Health Measurement Initiative Promoting Healthy Development Survey (FACCT, 2000)

[Note: Also included in the NIS/SLAITS Survey of Families with Young Children]

FOR PARENTS OF CHILDREN

In the last 12 months, how often did your child's doctors or other health providers:

- a. Take time to understand the specific needs of your child
- b. Respect you as an expert about your child
- c. Build your confidence as a parent
- d. Ask you how you are feeling as a parent
- e. Give you specific information to address any questions you may have about your child
- f. Understand your family and how you prefer to raise your child

(Response options: never, sometimes, usually, always)

Examples from the Child and Adolescent Health Measurement Initiative Living With Illness Module (FACCT/CAHPS, 2000)

FOR PARENTS OF CHILDREN WHO SCREEN POSITIVELY AS HAVING A CHRONIC CONDITION (USING THE LWIM SCREENER FOR IDENTIFYING CHILDREN WITH CHRONIC OR SPECIAL HEALTH CARE NEEDS)

- ◆ Does your child's personal doctor or nurse take the time to understand the specific needs of your child?
- ◆ In the last 12 months, how often did your child's doctors or other health providers give you support about the care you are providing for your child?
- ◆ Do you get the information you need from your child's doctors and other health providers about your child's medical or health conditions?

(Response options: never, sometimes, usually, always)

- ◆ In the last 12 months, how much of a problem, if any, was getting your child's doctors or other health providers to listen to your concerns about the best way to manage your child's medical or health problem?
- ◆ In the last 12 months, how much of a problem, if any, was getting your child's doctor or other health providers to follow up on concerns about your child's medical or health problems?

(Response options: a big problem, a small problem, not a problem, had no concerns)

Examples from Outcomes Measures for Health Education (Lorig, Stewart, Ritter, et. al, 1996)

FOR PEOPLE WITH A CHRONIC OR ONGOING HEALTH CONDITION

We would like to know **how confident** you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. Having an illness often means doing different tasks and activities to manage your condition. How confident are you that you can do all the things necessary to manage your condition on a regular basis?
2. How confident are you that you can judge when the changes in your illness mean you should visit a doctor?
3. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?
4. How confident are you that you can reduce the emotional distress caused by your health condition so that it does not affect your everyday life?
5. How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

(Response options: Not at all confident 1, 2, 3, 4, 5, 6, 7, 8, 9, 10 Totally confident)

Examples from the RWJ/FACCT/Harris National Survey (May, 2000)

FOR ALL ADULTS

Thinking about your overall ability to take care of your general health – eating right, getting check-ups, taking medicine, deciding when to see the doctor – how confident are you that you know what do to? (Response options: very confident, somewhat confident, not very confident, not at all confident)

Measure Category #3: Consumer Empowerment Example Survey Items

Specific Measurement Concept: Consumer Activation

Examples from the RWJ/FACCT/Harris National Survey (May, 2000)

FOR ALL ADULTS

Thinking about experiences you have had with health care professionals, such as doctors, how likely or unlikely you are to do the following:

- f. Get a second opinion on a serious diagnosis
- g. Look up information about a new prescription such as side effects and precautions
- h. Ask questions about medical equipment used for your medical treatment
- i. Get information on your health care professional's background before seeing them
- j. Try to learn about the quality of care provided before picking a doctor or health plan

(Response options: very likely, somewhat likely, not very likely, not at all likely)

Examples from the AHCPR/Kaiser Family Foundation Survey "Americans as health care consumers: The role of quality information"

FOR ALL ADULTS

22. Did you see ANY information comparing the QUALITY of health care among different...in the past 12 months, or not? (yes/no)

- a. health insurance plans
- b. doctors
- b. hospitals

(Recommended preamble for question #22: Not considering information about what benefits are covered or the cost of health care...)

60. How many books do you own about health, healthy living, or taking care of yourself? (none, 1-3, 4-9, 10 or more, don't know)

61. How often do you read magazines or newsletters about health, healthy living, or taking care of yourself? (regularly, sometimes, hardly ever, never, don't know)

**Measure Category #4: Patient Centered Systems of Care
Example Survey Items and/or System Assessment Tools**

Specific Measurement Concept: Understanding Population Needs and Preferences

CULTURAL COMPETENCY ASSESSMENT TOOLS

Three tools for providers and/or organizations and agencies to assess their knowledge, skills and attitudes regarding the cultural groups they serve were found and are summarized in the table below. Each of these tools are designed for use with multiple ethnic groups.

Summary of tools for assessing the cultural competency of organizations and providers

Name of tool	Description	Application and Administration	Status
Cultural Competence Self Assessment Protocol (Andrulis, Delbanco, Avakian, Shaw-Taylor, 1999)	Organizations rate their cultural competence in four areas: (1) relationship with the community, (2) relationships with staff (3) inter-staff relationships and (4) patient-provider relationships. A five point spectrum of cultural competence is suggested: Inaction; Symbolic Action and Initial Organization; Formalized Action; Internal and External Cultural Diversity Initiatives; The Cultural Diversity Learning Organization	Staff, community representatives and patients are interviewed using a set of provided questions and response options. No patient survey provided.	Tool has been fielded and appears to be a feasible and useful organizational self-assessment tool. Information about the validity or reliability of this tool is not available.
Cultural Competence Self-Assessment Questionnaire (Mason, 1995)	Providers and organizations can assess their cultural competency in seven areas: 1. Knowledge of communities; 2. Personal involvement; 3. Resources and linkages; 4. Staffing; 5. Service delivery and practice; 6. Organization policies and procedures; 7. Reaching out to community	Administrators and providers self-administer a survey tool. No patient survey provided.	SAME AS ABOVE
Monitoring the Managed Care of Culturally and Linguistically Diverse Populations (Tirado, 1998)	Three aspects of health plan cultural competency are reviewed: 1. Human resource capacity; 2. Policies and procedures; 3. Managing/monitoring. Three aspects of the cultural competency of providers are reviewed: 1. Knowledge; 2. Practice behavior; 3. Attitudes toward diversity. Plans and providers are rated on a five point spectrum: 1. Culturally resistant; 2. Culturally unaware; 3. Culturally conscious; 4. Culturally insightful; 5. Culturally versatile. Member survey mirrors plan/provider self assessment and is used as a comparison with plan/provider self assessment.	Self administered health plan, provider and member surveys available.	Tool has not been widely fielded or tested.
Assuring Cultural Competence in Health Care (The Office of Minority Health, PHS, USDHHS. 199)	A list of fourteen standards is available. If operationalized, these standards may form the basis of evaluations of the cultural competency of health care organizations. The three tools listed above attempt to operationalize many of the standards.	Tool not available	NA

Specific Measurement Concept: Patient Centered Customer Service and Convenience

NOTE: Few items were found regarding getting helpful information about services and how to navigate the system/use services or the convenience and comfort of health care services.

Example items from the Consumer Assessment of Health Plans Survey

FOR PEOPLE WHO HAVE BEEN ENROLLED WITH A HEALTH PLAN FOR A SPECIFIED PERIOD OF TIME (E.G. AT LEAST 6 MONTHS)

1. In the last 12 months, how much of a problem, if any, was it to get the help you needed when you called your health plan's customer service to get information or help for your child?
2. In the last 12 months, how much of a problem, if any, did you have with paperwork for your health plan?

Specific Measurement Concept: Managing for Patient Centered Care

Examples from the Improving Chronic Care initiative's Assessment of Chronic Illness Care (ACIC) (a system self-assessment tool)

How often does your organization:

- ◆ Set and review measurable goals for chronic illness care
- ◆ Incorporate goals for chronic illness care into business or quality improvement plans
- ◆ Have visible participation of senior leaders in improvement efforts around chronic illness care
- ◆ Develop formal agreements with community service agencies to enhance services for chronically ill patients
- ◆ Assess patient self-management needs by questionnaire
- ◆ Emphasize patients' active and central role in managing their illness
- ◆ Use interventions to address the psychosocial and emotional needs of chronically ill patients

(Response options: not at all, sometimes, quite a bit, often, almost always)

Examples from the Improving Chronic Care initiative's Planned Care Survey (a system self-assessment tool)

Regarding an improvement strategy for chronic illness care...

- ◆ Is ad hoc and not organized or supported consistently
- ◆ Utilizes ad hoc approaches for targeted problems as they emerge
- ◆ Utilizes a proven improvement strategy for targeted problems
- ◆ Includes a proven improvement strategy and uses it proactively in meeting organization goals

Example screener for identifying people with chronic conditions (FACCT, 2000)
(Used in RWJ/FACCT National Survey)

1. Do you currently need or use **medicine prescribed by a doctor** (other than vitamins)?
 - Yes → Go to Question 1a
 - No → Go to Question 2
 - 1a. Is this because of ANY medical, mental or other health condition?
 - Yes → Go to Question 1b
 - No → Go to Question 2
 - 1b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No

2. Do you need or use more **medical care , mental health or other health services** than is usual or routine for other people your same age?
 - Yes → Go to Question 2a
 - No → Go to Question 3
 - 2a. Is this because of ANY medical, mental or other health condition?
 - Yes → Go to Question 2b
 - No → Go to Question 3
 - 2b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No

3. Are you **limited or prevented** in any way in your ability to do things most people your age can do (for example, work, go to school, do housework, socialize, cook, pay bills)?
 - Yes → Go to Question 3a
 - No → Go to Question 4
 - 3a. Is this because of ANY medical, mental or other health condition?
 - Yes → Go to Question 3b
 - No → Go to Question 4
 - 3b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No

4. Do you need or get **special therapy**, such as physical, occupational or speech therapy?
 - Yes → Go to Question 4a
 - No → Go to Question 5
 - 4a. Is this because of ANY medical, mental or other health condition?
 - Yes → Go to Question 4b
 - No → Go to Question 5
 - 4b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No

5. Do you have any kind of mental or emotional problem for which you need or get **treatment or counseling**?
 - Yes → Go to Question 5a
 - No
 - 5a. Has this problem lasted or is it expected to last for at least 12 months?
 - Yes
 - No

What is the medical, mental or other health condition that you have that has lasted, or is expected to last, 12 months?
Please answer this question about the condition that has the biggest impact on your overall health and quality of life.
[SINGLE RESPONSE – pick most affecting]

- 01 Allergies
- 02 ALS (amyotrophic lateral sclerosis) or Lou Gehrig's disease
- 03 Alzheimer's disease
- 04 Arthritis
- 05 Asthma
- 06 Blindness or other vision impairment
- 07 Cancer
- 08 Chronic bronchitis
- 09 Chronic sinusitis
- 10 Chronic back problems
- 11 COPD (chronic obstructive pulmonary disease)
- 12 Depression
- 13 Developmental disability
- 14 Diabetes
- 15 Digestive or gastro-intestinal disorder
- 16 Epilepsy
- 17 Emphysema
- 18 Endometriosis
- 19 Fibromyalgia
- 20 Glaucoma
- 21 Hardening of the arteries
- 22 Hearing impairment
- 23 Heart disease
- 24 Hepatitis C
- 25 HIV/AIDS
- 26 Hypertension or high blood pressure
- 27 Kidney disease
- 28 Liver disease, including cirrhosis
- 29 Lupus
- 30 Lyme disease
- 31 Menopause
- 32 Migraine
- 33 Multiple sclerosis
- 34 Osteoporosis
- 35 Other mental health condition
- 36 Paralysis of the extremities
- 37 Parkinson's disease
- 38 Psoriasis
- 39 Stroke
- 40 Thyroid condition
- 96 Something else

Example Screening Questions for People Caring for Terminally Ill Family Members/Friends

(RWJ/FACCT/Harris National Survey, May, 2000)

Are you currently involved in caring for, or making health care decisions for, a terminally ill relative or close friend?

- 1 Yes JUMP TO Q248
- 2 No ASK Q246
- 3 Not sure ASK Q246
- 4 Decline to answer ASK Q246

For how long did you or have you cared for, or been involved in making health care decisions for, this person?
(READ LIST)

- 1 Less than one week
- 2 1 – 4 weeks
- 3 1 – 3 months
- 4 3 – 6 months
- 5 More than 6 months
- 6 Not sure (V)
- 7 Decline to answer (V)

ATTACHMENT B: Relevant National and State Surveys

Survey Name	Purpose	Periodicity of Surveys	Year Last Done:	Next Year to be Done:
National Health Interview Survey (NHIS)	A continuing survey and special studies to secure accurate and current statistical information on the amount, distribution, and effects of illness and disability in the United States and the services rendered for or because of such conditions. <i>Sample: household interview survey of civilian non-institutionalized population</i>	Annual	1999	2000
National Immunization Survey (NIS)	This survey asks questions about childhood immunization for children 19-35 months of age and requests parental permission for contacting children's vaccination providers. <i>Sample: household interview survey of civilian non-institutionalized survey</i>	Annual since 1994, changed in 1996	1999	2000
SLAITS: Survey of Families with Young Children	This survey asks questions about doctor's visits for children 4-35 months of age. Parents are asked about their experiences with pediatricians, family practitioners, or other children's health providers. Parents are also asked about the ways they keep their children healthy at home.	1 st year?	2000	2000
SLAITS: Survey of Children with Special Health Care Needs	This survey asks about the health care needs and health insurance coverage of children under 18 years of age. Data will be used to estimate the number of children with special health care needs in each State, to describe the types of services that they need and use, and to assess the need for additional services.	1 st year?	2000	2000
Medical Expenditures Panel Survey	The Medical Expenditure Panel Survey (MEPS) is a nationally representative survey. Data collected from the MEPS include demographic characteristics, health conditions, health status, use of medical care services, charges and payments, access to care, satisfaction with care, health insurance coverage, income, and employment medical expenditure data continuously at both the person and household levels through an overlapping panel design. In this design, two calendar years of information are collected from each household in a series of five rounds of data collection over a 2 1/2-year period of time.	This series of data collection activities is repeated each year on a new sample of households, resulting in overlapping panels of survey data.		
National Survey of Family Growth (NSFG)	A multipurpose survey based on personal interviews with a national sample of women 15-44 years of age in the civilian non-institutionalized population of the United States. Its main function is to collect data on factors affecting pregnancy and women's health in the United States <i>Sample: Household survey of 10,000 women</i>	Sporadic: 1973, 1976, 1982, 1988, 1990, 1995	1995	Not clear

Survey Name	Purpose	Periodicity of Surveys	Year Last Done:	Next Year to be Done:
National Health Care Survey (NHCS)	This survey is a source of a wide range of data on the health care field and a significant resource for monitoring health care use, the impact of medical technology, and the quality of care provided to a changing American population. Built upon the National Hospital Discharge Survey, the National Ambulatory Medical Care Survey, the National Nursing Home Survey, and the National Health Provider Inventory. Sample: Records based study.	Sporadic: (different survey titles) 1963, 1971-76, 1986, 1991	1991	Not clear
National Maternal and Infant Health Survey (NMIHS)	The objective of this survey is to collect data needed by Federal, State, and private researchers to study factors related to poor pregnancy outcomes, including low birth weight, stillbirth, infant illness, and infant death. The NMIHS is a follow back survey—it follows back informants on vital records.	1988 survey, 1991 longitudinal follow-up	1988 with 1991 longitudinal follow-up	Not clear
National Mortality Followback Survey (NMFS)	This survey is designed to supplement information from death certificates in the vital statistics file with information on important characteristics of the descendant. These include the use of health services prior to death, socioeconomic status, aspects of life style, health care utilization prior to death, and other factors that may affect when and how death occurs.	1986, 1993	1993	Not clear
National Ambulatory Medical Care Survey (NAMCS)	A national survey designed to collect data on the utilization and provision of ambulatory care services in hospital emergency and outpatient departments. Sample: Medical records survey	Annually from 1974-1981, in 1985, and annually again since 1989	Probably in 1999	2000
National Home and Hospice Care Survey (NHHCS)	A continuing series of surveys of home and hospice care agencies in the United States. Information was collected about agencies that provide home and hospice care and about their current patients and discharges.	1992, 1993, 1994, 1996	1996	Not clear
National Nursing Home Survey (NNHS)	A continuing series of national sample surveys of four nursing homes, their residents, and their staff.	1973-74 1977 1985 1995	1995	Not clear
National Employer Health Insurance Survey	A national survey of businesses, both private and public sector that will provide national and state level analysis of private health insurance and will examine characteristics of employer sponsored health insurance.	1994	1994	Not clear

Survey Name	Purpose	Periodicity of Surveys	Year Last Done:	Next Year to be Done:
Behavioral Risk Factor Survey	A state-based survey that collects data on the behaviors and conditions that place adults at risk for the chronic diseases, injuries and preventable infectious diseases that are the leading causes of morbidity and mortality in the United States. (humans) <i>Sample: Non-institutionalized civilians over age 18 living in households with a telephone.</i>	Monthly	Ongoing	Ongoing
Youth Risk Behavioral Factor Survey	The YRBS provides vital information on risk behaviors among young people to more effectively target and improve health programs. CDC conducts national surveys <i>Sample: A representative sample of students in grades 9–12 in both public and private schools in the 50 states and the District of Columbia.</i>	Every 2 years nationally	1997, 1999	2001
The National Alternative High School Youth Risk Behavior Survey	To provide critical information on health risk behaviors among young people in high-risk situations. <i>Sample: A representative sample of almost 9,000 students in alternative schools.</i>	1998	1998	
The National College Health Risk Behavior Survey	To provide critical information on health risk behaviors among young people in college <i>Sample: a representative sample of about 5,000 undergraduate students.</i>	1995	1995	
School Health Index	Assessment tool for schools and school districts to assess where they stand for healthy behaviors and to improve their performance.		1999	